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### Sexual health needs

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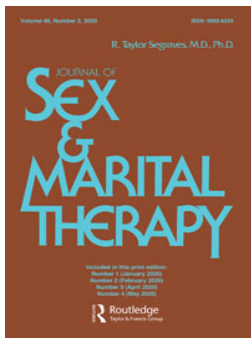
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## Sexual Health Needs: How Do Breast Cancer Patients and Their Partners Want Information?

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### ABSTRACT

It is well known that breast cancer treatment can affect sexuality. This survey evaluated the needs of breast cancer patients and partners regarding sexual care. The majority of patients (80.4%) and partners (73.7%) did not receive any information regarding sexuality. Although only a quarter of all respondents reported a direct need for information regarding sexuality, most valued an opportunity to discuss sexuality. The nurse practitioner was the most preferable care provider to provide information about sexuality, supported by a brochure or website. Patients considered during treatment as most suitable timing of discussing sexuality, and partners before the start of treatment.

### Introduction

Breast cancer is the most common type of cancer among women (IARC, 2017; Wendt, 2017). Since the number of breast cancer survivors has increased in past years due to more effective treatment, there is more attention for improving patient's well-being and quality of life (Kool et al., 2016). Sexual functioning is considered to be an important aspect of quality of life and is included in the latest set of value-based patient-centered outcomes for women with breast cancer (Ong et al., 2016). Sexual problems are common after breast cancer treatment, with an estimated prevalence up to 85% (Chang, Chang, & Chiu, 2018; Panjari, Bell, & Davis, 2011; Ussher, Perz, & Gilbert, 2013). Breast cancer treatment, including surgical treatment, radiotherapy, chemotherapy, hormonal therapy, and immunotherapy can cause physical sexual problems, such as problems with vaginal lubrication, decreased nipple sensation, and reduced desire due to treatment-induced menopause (Arraras et al., 2016; Biglia et al., 2010; Bober & Varela, 2012; Montazeri et al., 2008; Raggio, Butryn, Arigo, Mikorski, & Palmer, 2014). Besides, psychological sexual problems, e.g., disturbance in body image and physical unattractiveness, could affect sexual function regardless of treatment (Boquiren et al., 2016; Figueiredo, Cullen, Hwang, Rowland, & Mandelblatt, 2004;

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Radina, Fu, Horstman, & Kang, 2015; Teo, Novy, Chang, Cox, & Fingeret, 2015; Teo et al., 2016). The negative effect of sexual problems on patients' well-being has been well studied (Badhwar, Bhama, Vakhariya, & Goodman, 2014; Biglia et al., 2010; Boquiren et al., 2016; Dizon, Suzin, & McIlvenna, 2014; Panjari et al., 2011; Raggio et al., 2014). Moreover, sexual problems affect not only patients; their partners are likely to suffer as well (Hawkins et al., 2009; Nakaya et al., 2010; Pluchino et al., 2016; Rowland & Metcalfe, 2014). As a consequence, relationships and sexuality may change (Keesing, Rosenwax, & McNamara, 2016; Pluchino et al., 2016). Partners do experience these changes as a struggle (Albaugh, Sufrin, Lapin, Petkewicz, & Tenfelde, 2017; de Groot et al., 2005; Hawkins et al., 2009; Miaja, Platas, & Martinez-Cannon, 2017). Attention for patient-partner relationship is important since being in an intimate relationship with affectionate behavior and emotional closeness is associated with better (psychosocial) outcomes and adaptation to disease in both cancer patients and partners (Kroenke et al., 2017; Pistrang & Barker, 1995; Rottmann et al., 2017; Zimmermann, 2015).

Adequate information and support regarding intimacy and sexuality can reduce distress in patients and partners (Bober & Varela, 2012; Canzona et al., 2016). Despite the growing literature on the importance of information about sexuality and patients' preferences about its communication, several studies identified that health care providers in the field of oncology do not routinely provide information on sexuality or discuss this subject with their patients and partners (Butcher et al., 2016; Faghani & Ghaffari, 2016; Flynn et al., 2012; Gilbert, Perz, & Ussher, 2016; Krouwel, Hagen et al., 2015; Krouwel, Nicolai, van der Wielen et al., 2015; Miaja et al., 2017; Reese et al., 2019; Stead, Brown, Fallowfield, & Selby, 2003; Ussher, Perz, Gilbert, Wong et al., 2013; Wang et al., 2013; Wiggins, Wood, Granai, & Dizon, 2007). As a result, patients and partners receive little support for sexual health issues (Keesing et al., 2016). Previous research showed that patients and partners do consider information about sexuality and relationships as important (Gilbert, Ussher, & Hawkins, 2009; McClelland, 2016; Ussher, Perz, & Gilbert, 2015; Wendt, 2017) and they prefer to receive oral as well as written information regarding sexuality (Ussher, Perz, & Gilbert, 2013). Existing literature describes preferences of breast cancer patients about oral patient-provider communication regarding sexuality. Patients prefer an open discussion about sexuality with a health care provider where the provider initiated sexuality during a conversation, normalized sexuality-related issues, and acknowledged the magnitude of the subject (Canzona et al., 2016; Gilbert et al., 2016; Reese et al., 2017). Less is known about the breast cancer patients' and survivors' preferred modality of written information provision (Ussher, Perz, & Gilbert, 2013). Moreover, little is known on the preferred type of health care provider to discuss sexuality with and suitable timing for information. Besides, partners' preferences on communication about sexuality may differ from patients' preferences and their view is less described in previous literature (Gilbert et al., 2016). It is unknown whether preferences of partners differ from patients' preferences.

Hence, we aimed to evaluate patients' and partners' preferences of written information regarding sexuality, their most preferred health care professional with whom to discuss sexuality, and what timing is considered to be most suitable moment for discussing sexuality.

## Material and methods

This multicenter study was conducted between March and December 2017. Data for this cross-sectional study were collected using a questionnaire. Female patients who were treated for noninvasive or invasive breast cancer between January 2015 and December 2016 at University Cancer Center Leiden–The Hague and the Groene Hart Hospital (Gouda) in the Netherlands were selected. Exclusion criteria were patients younger than 18, patients with a benign breast tumor, and patients who moved abroad. No selection criteria according to maximum age of the patients was made.

Invitation letters explaining the purpose of the study including an informed consent form were sent by post to patients. All patients also received an extra invitation for a partner. After informed consent was obtained, the questionnaires were sent by post or email, according to the preference of the respondent. If the patient declined participation, the partner could still be included and vice versa. According to the advice of the Medical Ethics Committee of the Leiden University Medical Center, the information letters were only sent once; no further attempt was made if the permission form was not returned.

### **Questionnaire**

The questionnaires were developed by the authors and were based on the study aim and review of literature. Structure and design of these questionnaires were derived from questionnaires used in previous studies performed by our research institute to evaluate sexual health care (Krouwel, Hagen et al., 2015; Krouwel, Nicolai, van der Wielen et al., 2015; Krouwel, Nicolai, van Steijn-van Tol et al., 2015; Nicolai et al., 2013; van Ek et al., 2015). The questionnaire developed for breast cancer patients consisted of 57 items assessing topics such as demographic factors, sexual function before and after diagnosis, their experiences and satisfaction with current sexual health care, and their preferences regarding sexual health care (Appendix A). A comparable questionnaire was designed for the partners of the breast cancer patients. It consisted of 37 items, assessing demographic factors, their experiences with sexuality during the treatment process of their partner, and their preferences on sexual health care (Appendix B).

The questionnaires were pilot tested by a specialized test panel of the Dutch Breast Cancer Society (Borstkankervereniging Nederland). The questionnaire for partners was pilot tested by partners of the test panel. The questionnaire was adjusted according to their comments; for example, linguistic adjustments were made, and open-ended options as well as questions on changes of body image were added.

### **Privacy**

All data containing personal information of participants were stored securely, and only authorized members of the research team had access to the data. After informed consent was obtained, the participants received an identification code to ensure privacy.

### **Statistical analysis**

All data were analyzed using IBM SPSS statistics 23 (SPSS Inc., IBM Corp., Armonk, New York). Demographic information and responses to the survey were analyzed using descriptive statistics. Difference in age between respondents and nonrespondents was calculated using the independent sample *t* test. Bivariate and multivariate associations were calculated using the Pearson's Chi-square test and Fisher's exact test. In Table 2, oncologist, surgeon, radiotherapist, and plastic surgeon were merged to "physician" since some patients might not have consulted each one individually. Outcomes were considered statistically significant if the two-sided *p* values were  $<.05$ .

### **Ethics**

The research protocol was approved by the Medical Ethics Committee of the Leiden University Medical Center and the scientific office of Haaglanden Medical Center and Groene Hart Hospital (P16.279). Approval was needed since the questionnaires consisted of sensitive questions.

## Results

### *Sample*

In total, 1,098 breast cancer patients were invited to participate in the study, and 208 agreed to participate (19%). The remaining group did not respond. Thirty-five women who gave their consent did not return the questionnaire. Subsequently, a total of 173 patient questionnaires and 76 partner questionnaires were analyzed.

### *Demographic and clinical characteristics*

The responding patients had a mean age of 60.1 years (standard deviation: 11 years, range 29–91 years). No significant difference in age was found between responders and nonresponders (mean difference  $-0.5$ ; 95% confidence interval  $-2.4, 1.4$ ;  $p = .6$ ). Of the respondents, 106 women (62.4%) had local breast cancer. The majority of the women underwent breast-conserving surgery (66.5%) in combination with external radiotherapy (54.9%).

In the group of partners, the median age was 61 years (range 33–79). The majority was male ( $n = 69$ , 93.3%). All characteristics of the respondents are summarized in [Table 1](#).

### *Patients' preferences on information regarding sexuality*

The majority of respondents (80.4%,  $n = 135$ ) stated to not have received any information about effect of their breast cancer on sexuality. A quarter (24.9%,  $n = 42$ ) reported a need for information regarding sexuality; of them, 62.0% ( $n = 26$ ) did not receive any information.

To the assumption that every breast cancer patient should be offered an opportunity to discuss sexuality, 47.6% agreed, 20.0% disagreed, and 32.4% gave neutral answers.

We asked the participants how they would prefer to receive information regarding sexuality. Around half of the responding breast cancer patients ( $n = 84$ , 48.6%) answered positively to the suggestion of a brochure with information about sexuality. To the suggestion that information was provided via a website, 35.3% ( $n = 61$ ) of the respondents agreed and 27.2% ( $n = 47$ ) preferred a conversation with a health care professional to obtain information regarding sexuality.

To the question of which health care provider they would prefer to discuss sexuality with, 51% ( $n = 88$ ) answered positively to the assumption this would be with a nurse practitioner. Sexologist ( $n = 29$ , 17%) and general practitioner ( $n = 28$ , 16%) were the next most mentioned. Seventeen percent ( $n = 29$ ) agreed to the suggestion that they do not have a need to have conversation with a health care provider about sexuality. Next, participants' view on most appropriate timing were asked. Half of the patients ( $n = 81$ , 46.6%) considered during treatment as the most suitable moment to discuss sexuality. On the assumption the best moment would be before treatment, 32.4% ( $n = 56$ ) agreed, and a quarter ( $n = 43$ , 24.9%) preferred the end of treatment. All preferences according all formats of information, preferred health care professionals, and timing are displayed in [Table 2](#).

If sexuality was discussed by a health care provider, the majority of the patients in a relationship (61.3%,  $n = 68$ ) stated the presence of their partner as important. The rest ( $n = 43$ , 38.7%) considered it as not important. Half of the patients ( $n = 54$ , 48.6%) stated that every partner should be offered an opportunity to discuss sexuality with a health care provider. A third were neutral ( $n = 37$ ) and 18% ( $n = 20$ ) disagreed with this assumption.

**Table 1.** Baseline characteristics of the respondents.

	Patients ( <i>n</i> = 173) <i>n</i> (%)	Partners ( <i>n</i> = 76) <i>n</i> (%)
<b>Age (years)</b>	Mean 60.1 (SD = 11)	Median 61.00 (SD = 33–79)
<b>Gender</b>		
Female	173 (100)	5 (6.8)
Male	0 (0)	67 (93.2)
<b>Relationship (years)</b>	Median 28.4 (range 1–55)	
<b>Marital status</b>		
Single	27 (15.6)	
In a relationship	128 (74.0)	
Widow	18 (10.4)	
<b>Education*</b>		
Non or elementary school	5 (2.9)	2 (2.6)
Middle-level applied	46 (27.1)	9 (11.8)
Intermediate vocational	25 (14.7)	18 (23.7)
High school	28 (16.5)	7 (9.2)
Bachelor degree or higher	66 (38.8)	40 (52.6)
<b>Work*</b>		
Yes	71 (42.5)	44 (57.9)
No, job seeker	6 (3.6)	2 (2.6)
No, not able due to illness	15 (9.0)	0 (0)
No, retiree	64 (38.3)	27 (35.5)
Other	11 (6.6)	3 (3.9)
<b>Stage*</b>		
DCIS	28 (16.5)	
Local breast cancer	106 (62.4)	
Metastases in the axilla	33 (19.4)	
Metastases elsewhere	3 (1.8)	
<b>Type of surgery</b>		
Non	3 (1.5)	
Breast-conserving surgery	115 (58.1)	
Mastectomy, without reconstruction	24 (12.1)	
Mastectomy, with reconstruction	32 (16.2)	
Axillary lymph node dissection	24 (12.1)	
<b>Additional treatment**</b>		
None	21 (12.1)	
Neo-adjuvant chemotherapy	29 (16.8)	
Chemotherapy	28 (16.2)	
Radiotherapy	95 (54.9)	
Intra-operative radiation therapy	21 (12.1)	
Hormonal therapy	50 (28.9)	
Immunotherapy	16 (9.2)	

\**n* differs because some respondents skipped the question.

\*\**n* differs due to multiple answers that could be given to this question.

SD = standard deviation; DCIS = Ductal carcinoma in situ.

## Partners

Of all partners, 73.7% (*n* = 56) stated to not have received any information about possible sexuality problems due to cancer. A quarter (*n* = 19) reported a need for information regarding sexuality; half of them (*n* = 9, 47%) received this information. The nurse practitioner was the most preferred health care professional (*n* = 40, 52.6%) with whom to discuss sexuality. Partners mostly preferred to receive information via a brochure (*n* = 31, 40.8%). In comparison to the responding patients, partners were less likely to gain information via the breast cancer association (*p* = .02). Significantly more partners (*n* = 38, 50%) than responding patients (*n* = 56, 32.4%) considered before treatment as the best moment to discuss sexuality (*p* = .01). More than half of the partners (*n* = 42, 55.3%) stated their involvement during sexual counseling of their partners as important, 42.1% (*n* = 32) left it up to their partners and 2.6% (*n* = 2) considered their presence as not important. To the suggestion that every partner should be offered an opportunity to discuss sexuality with a health care provider, 40% (*n* = 30) agreed, 22.7% (*n* = 17) disagreed, and 37.3% (*n* = 28) gave neutral answers.



**Table 2.** Patients and partners with an information need: Preference on format, health care provider, and timing for receiving information regarding sexuality.

	Patients <i>n</i> (%)	Partners <i>n</i> (%)	<i>p</i> value
<b>Format*</b>			
Brochure	84 (68.2)	31 (55.4)	ns
Website	61 (49.6)	26 (46.4)	ns
Consultation with professional	47 (38.2)	26 (46.4)	ns
Via the breast cancer association	32 (26.0)	6 (10.7)	.02
Via a patient forum	18 (14.6)	6 (10.7)	ns
App	16 (13.0)	7 (12.5)	ns
Group session with a professional	14 (11.4)	4 (7.1)	ns
Via the cancer society	12 (9.8)	5 (8.9)	ns
Via fellow patients	12 (9.8)	6 (10.7)	ns
<b>Health care provider*</b>			
Nurse practitioner	88 (64.2)	40 (65.6)	ns
Physician	39 (22.5)	21 (34.4)	ns
Sexologist	29 (21.1)	9 (14.8)	ns
General practitioner	28 (20.4)	17 (28.9)	ns
Psychologist	20 (14.6)	8 (13.1)	ns
Social worker	10 (7.3)	3 (4.9)	ns
<b>Timing*</b>			
Before treatment	56 (32.4)	38 (50.0)	.01
During treatment	81 (46.8)	23 (30.3)	.02
After treatment	43 (24.9)	21 (27.6)	ns

\* *n* differs due to multiple answers that could be given to this question.

## Discussion

It is well known that women with breast cancer and their partners frequently experience negative changes in their relationship and sexuality (Hawkins et al., 2009; Nakaya et al., 2010; Nasiri, Taleghani, & Irajpour, 2012; Pluchino et al., 2016; Rowland & Metcalfe, 2014). Although most patients and partners in our survey did not report a direct need for information regarding sexuality, most valued an opportunity to discuss sexuality. Both patients and partners prefer to receive information via a breast cancer practitioner through a website or brochure. Patients think during treatment is the most suitable timing to discuss sexuality. However, partners would like to discuss sexuality at the beginning of treatment.

In concordance with previous literature, the current study confirms that sexuality is not routinely discussed by health care providers with patients and their partners, with most respondents not having received information regarding sexuality (Chang et al., 2018). However, the reported need for information reported by patients in our study (24.9%) was lower compared to results of two previous studies (60%–70%) which investigated information need regarding sexuality in breast cancer patients who were recruited via breast cancer associations (Den Ouden, Pelgrum-Keurhorst, Uitdehaag, & De Vocht, 2018; Ussher, Perz, & Gilbert, 2013). The information need in partners in our study was comparable with the need of the responding patients (both 25%). However, partners in our study valued an opportunity to discuss sexuality with a health care provider and wanted to be present when sexuality was discussed with their partners. It is important for health care providers to involve partners, as literature reveals that partners who did not receive accurate information are more distressed than partners who felt well informed (Mireskandari et al., 2006). Moreover, previous literature reported that breast cancer patients do consider information for their partners as very important (Ussher, Perz, & Gilbert, 2013). Partners may not always be present when sexuality is discussed during a consultation with a health care provider. Therefore, written information about sexuality might be helpful for partners to be informed about possible sexuality issues (Mireskandari et al., 2006). Patients and partners prefer written information via a brochure or website. Partners were less likely than their patients to obtain their information via the breast cancer association. It can be argued that information



should be offered in multiple ways to meet patients' and partners' preferences and reach them as much as possible.

Suitable timing for communication about sexuality is essential. We found a difference in preferences of patients and partners in terms of most suitable timing to discuss sexuality. However, both patients and partners suggest that there should be multiple moments during the treatment trajectory to discuss sexuality. Previous research that investigated the need for information regarding sexuality in breast cancer patients who were diagnosed five years ago stressed the importance of appropriate timing of information; namely, at least shortly after the treatment started (Den Ouden et al., 2018). This is important since patients and partners might underestimate the influence of treatment on sexuality at the start of or during treatment (Dikmans, van de Grift, Bouman, Pusic, & Mullender, 2019). Moreover, it is known that patients and partners found it difficult to raise a discussion about sexuality. Lack of communication about the subject may lead to problems with coping and conflicts between couples (Holmberg, Scott, Alexy, & Fife, 2001; Rowland & Metcalfe, 2014; Sandham & Harcourt, 2007). Discussing sexuality with patients and partners before the start of treatment would be helpful to inform them about possible changes in sexuality and to manage expectations. Including sexuality in consultations repeatedly through the treatment process and follow-up is advised since the need for information and support regarding sexuality changes over time (Den Ouden et al., 2018). The implementation of fixed moments during treatment and follow-up to discuss the topic might have added value (Dikmans et al., 2018; Stabile et al., 2017).

In line with the literature, patients and partners reported to feel most comfortable to discuss sexuality with a nurse practitioner (Den Ouden et al., 2018; Ussher, Perz, & Gilbert, 2013). The nurse practitioner plays a coordination role in the treatment process and supports the patients during the whole treatment and follow-up. Previous studies reveal that nurses do feel responsible for bringing up sexuality, but they encounter several barriers such as lack of time and lack of training (Krouwel, Nicolai, van Steijn-van Tol et al., 2015). Nurse practitioners could assume responsibility within a multidisciplinary team for discussing the subject with the breast cancer patients and partners. For implementation into practice, nurse practitioners should have access to training and (written) information regarding sexuality. It would be useful if written material, such as a brochure or website, is easily available to everyone to empower patients and partners themselves. New approaches to enhance sexual care for patients and their partners, such as Internet tools and interventions, are promising and interesting for further research (Hummel et al., 2017, 2019; Jones & McCabe, 2011).

### **Study limitations**

To our best knowledge, this is the first study that evaluated the information needs regarding sexuality and relationship of breast cancer patients and partners at the same moment. This paper adds new insights on preferences of partners regarding information about sexuality and explored the differences with the preferences of their partners. A number of limitations need to be considered. First, we used a nonvalidated questionnaire, since there are no validated questionnaires available. Second, our response rate was low, which might have resulted in bias. Explanations for the response rate are timing of the questionnaire (shortly after diagnosis), the sensitivity of the subject, and the fact that no permission was obtained to send a reminder or ask for reasons for refusal. Our findings should be interpreted carefully and may be not generalizable for all breast cancer patients and partners. This is one of the few studies exploring the differences between preferences of patients and partners with regard to sexuality-related information. Therefore, the results of this study might be a starting point for further exploration. Longitudinal studies of interventions based on preferences of patients and partners and studies that measure pre- and post-comfort with sexuality communication after receiving information are needed.

At the moment, sexual health care seems not to be a standard part of breast cancer care in the first two years after breast cancer diagnosis. Most of the respondents, patients and partners, did not report a direct need for information regarding sexual problems during this survey, but value an opportunity to discuss the subject if needed. The most suitable moment for such a consultation was considered to be at the beginning of or during treatment, provided by a nurse practitioner, and supported by a brochure or website. It is advised to offer an opportunity to discuss sexuality with patients and partners at multiple moments during treatment and follow-up.

## Conflicts of interest

The authors report no conflicts of interest.

## Data statement

Herewith I state to have full control of all primary data and I agree to allow the journal to review our data if requested.

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## Appendix A

### Questionnaire (translated from Dutch)

For each question chose the most suitable answer. Thank you in advance for your effort.

#### Part 1: Demographics

1. What is your age? \_\_\_\_\_ years
2. What is your ethnicity?
  - ☐ Dutch
  - ☐ Other: \_\_\_\_\_
3. What is your marital status?
  - ☐ Single
  - ☐ In a relationship, living together
  - ☐ In a relationship, not living together
  - ☐ Married
  - ☐ Widowed
  - ☐ Other: \_\_\_\_\_
4. If you are in a relationship, for how long?
  - ☐ ... years
5. Level of education?
  - ☐ Elementary school
  - ☐ Middle school
  - ☐ High school
  - ☐ College
  - ☐ University
  - ☐ Other: ... ..
6. Are you currently employed?
  - ☐ Yes
  - ☐ No, I am in between jobs
  - ☐ No, not able to work due to my illness
  - ☐ No, I am retired
  - ☐ Other: \_\_\_\_\_

#### Part 2: Diagnosis and treatment

7. Which stage of breast cancer do you have/had?
  - ☐ A premalignant stage (ductal carcinoma in situ)
  - ☐ Breast cancer only in the breast itself
  - ☐ With metastasis in the axilla(s)
  - ☐ With metastasis elsewhere in the body
8. How long ago were you diagnosed with breast cancer?
  - ☐ 0–3 months ago
  - ☐ 3–6 months ago
  - ☐ 6 months–1 year ago
  - ☐ 1–2 years ago
  - ☐ More than 2 years ago

9. Which surgical treatments did you underwent? *(multiple answers possible)*
  - ☐ No operation
  - ☐ Breast-conserving surgery
  - ☐ Mastectomy, without construction of the breast
  - ☐ Mastectomy, with direct construction of the breast
  - ☐ Mastectomy, with secondary reconstruction of the breast
  - ☐ Mastectomy of both breasts, without construction
  - ☐ Mastectomy of both breasts, without direct construction
  - ☐ Mastectomy of both breasts, without secondary construction
  - ☐ Axillary lymph node dissection, one side
  - ☐ Axillary lymph node dissection, both sides
10. Did you receive, besides surgery, other treatments? *(multiple answers possible)*
  - ☐ No
  - ☐ Radiotherapy after the operation
  - ☐ Radiotherapy during the operation
  - ☐ Chemotherapy before surgery
  - ☐ Chemotherapy after surgery
  - ☐ Endocrine therapy
  - ☐ Immunotherapy (Herceptin)
11. To what extent were you concerned about your health when you heard the diagnosis of breast cancer?
  - ☐ No concerns
  - ☐ Some concerns
  - ☐ Many concerns
  - ☐ Grave concerns
12. Have your concerns changed **after** treatment?
  - ☐ Yes, my concerns are increased
  - ☐ Yes, my concerns are declined
  - ☐ No, my concerns didn't change
  - ☐ No, I had no concerns
13. If you are breast cancer-free, are you afraid that the breast cancer may come back?
  - ☐ Inapplicable
  - ☐ Not afraid
  - ☐ A bit afraid
  - ☐ Afraid
  - ☐ Very afraid

**Part 3: Your experience about intimacy and sexuality after disease**

14. Were you sexually active **before** the diagnosis of breast cancer?
  - ☐ Yes
  - ☐ No
15. Did you experience complaints in intimacy or sexuality before the diagnosis of breast cancer?
  - ☐ Yes, go to question 16
  - ☐ No, go to question 18
16. Which intimacy or sexuality complaints did you have? *(multiple answers possible)*
  - ☐ Fatigue
  - ☐ Feel uncertain about my appearance
  - ☐ Less intimacy with my partner
  - ☐ Not enjoying sex anymore
  - ☐ No sex drive
  - ☐ Difficulties with orgasms
  - ☐ Pain during intercourse
  - ☐ Insufficient lubrication
  - ☐ Other: \_\_\_\_\_
17. Did the intimacy or sexuality complaints changes **after** the diagnosis of breast cancer?
  - ☐ No, complaints didn't change
  - ☐ Yes, complaints have disappeared
  - ☐ Yes, complaints have declined
  - ☐ Yes, complaints have increased
  - ☐ Yes, complaints have changed
18. Are you **after** treatment sexually active?
  - ☐ Yes



☐ No

19. Did you experience new complaints with regard to intimacy or sexuality due though the breast cancer or the treatment?

☐ Yes, go to question 20

☐ No, go to question 25

20. Which complaints did you experience? (*multiple answers possible*)

☐ Fatigue

☐ Feel uncertain about my appearance

☐ Feel uncertain about changes body image

☐ Less intimacy with my partner

☐ Not enjoying sex anymore

☐ No sex drive

☐ Difficulties with orgasms

☐ Pain during intercourse

☐ Insufficient lubrication

☐ Menopausal complaints

☐ Other: \_\_\_\_\_

21. On a scale of 0 to 10, in which amount did you suffer from these complaints?

0 means no suffering, 10 means a lot of suffering

Grade: ... ..

22. Did one of your therapists ever offered you help for these complaints?

☐ Yes, by advising tools (for example, lubricant)

☐ Yes, by tips on other forms of intimacy

☐ Yes, other: \_\_\_\_\_

☐ No, go to question 25

23. Were you satisfied with the help you were offered?

☐ Yes

☐ No

24. Are you referred, by your therapist, for your sexual of intimacy complaints?

☐ Yes, to: \_\_\_\_\_ (for example other specialist or sexologist)

☐ No, but I would have wanted a referral

☐ No, I had no need of a referral

#### **Part 4: Information about intimacy and sexuality**

25. Did you need information about possible intimacy or sexuality complaints due to breast cancer and treatment?

☐ Yes

☐ No

26. Did you at some point receive any information about intimacy and sexuality and possible complaints due to treatment?

☐ Yes, **go to question 27**

☐ No, **go to question 31**

27. At what stage did you receive the information about intimacy and sexuality? (*multiple answers possible*)

☐ At the same time as the diagnosis of breast cancer

☐ Before chemotherapy and before surgery

☐ Before the operation

☐ After the operation

☐ Before the additional treatment\*

☐ During the additional treatment\*

☐ At the end of all treatments

☐ Other: \_\_\_\_\_

\*Additional treatment means chemotherapy, radiotherapy, and/or endocrine therapy

28. Did you have to ask for information about intimacy or sexuality?

☐ Yes, I had to ask for this information by myself

☐ No, the care provider gave the information

☐ No, it was clear to me where I could find information (for example, a flyer or on the web)

29. Who gave you the information about intimacy and sexuality? (*multiple answers possible*)

☐ General practitioner

☐ Surgeon

☐ Nurse in the breast cancer outpatient clinic

☐ Oncologist

☐ Radiotherapist



- ☐ Plastic surgeon
  - ☐ Psychologist
  - ☐ Sexologist
  - ☐ Social worker
  - ☐ Someone else: \_\_\_\_\_
30. How did you receive information about intimacy and sexuality? (*multiple answers possible*)
- ☐ Patient flyer
  - ☐ Via other (breast) cancer patients
  - ☐ By an information moment for patients with breast cancer
  - ☐ By Dutch Breast Cancer Society (Borstkankervereniging Nederland)
  - ☐ By Dutch Cancer Society (KWF Kankerbestrijding)
  - ☐ By a webpage about breast cancer and sexuality
  - ☐ In a conversation with a health care professional
  - ☐ Other: \_\_\_\_\_
31. Did you actively search for information about intimacy and sexuality? (*multiple answers possible*)
- ☐ No, I didn't search for information
  - ☐ Yes, on the Internet
  - ☐ Yes, via Dutch Breast Cancer Society (Borstkankervereniging Nederland)
  - ☐ Yes, via Dutch Cancer Society (KWF Kankerbestrijding)
  - ☐ Yes, via other (breast) cancer patients
  - ☐ Yes, via family or friends
  - ☐ Other: \_\_\_\_\_
32. Are you satisfied with the information about intimacy and sexuality?
- ☐ Yes, go to question 34
  - ☐ No, **go to question 33**
  - ☐ Inapplicable, **go to question 34**
33. What could have been better about the information? (*multiple answers possible*)
- ☐ The amount was insufficient
  - ☐ The information was too general; it was not about my situation
  - ☐ The content of the information was incorrect
  - ☐ The moment of the information was too late
  - ☐ The moment of information was too early
  - ☐ I have asked for information, but I didn't receive any
  - ☐ The health care professional should have given me the information
  - ☐ I have no need for information
  - ☐ Other: \_\_\_\_\_
34. What is, according to you, the best way of receiving information about intimacy and sexuality? (*multiple answers possible*)
- ☐ Patient flyer
  - ☐ Via an application on a tablet or phone (e-health)
  - ☐ By a webpage about breast cancer and sexuality
  - ☐ By Dutch Breast Cancer Society (Borstkankervereniging Nederland)
  - ☐ By Dutch Cancer Society (KWF Kankerbestrijding)
  - ☐ By a patient forum on the Internet
  - ☐ By a group meeting with other patients lead by a health care professionals
  - ☐ In a conversation with other (breast) cancer patients
  - ☐ In a conversation with a health care professional
  - ☐ None, I have no need for information
  - ☐ Other: \_\_\_\_\_
35. At which moment, during treatment, would you prefer to receive information about intimacy and sexuality? (*multiple answers possible*)
- ☐ At the same time as the diagnosis of breast cancer
  - ☐ Before chemotherapy and before surgery
  - ☐ Before the operation
  - ☐ After the operation
  - ☐ Before the additional treatment\*
  - ☐ During the additional treatment\*
  - ☐ At the end of all treatments
  - ☐ Other: \_\_\_\_\_

\* Additional treatment means chemotherapy, radiotherapy, and/or endocrine therapy.

**Part 5: Discussing intimacy and sexuality with a health care professional**

36. Who should, according to you, initiate the discussing about intimacy and sexuality?
- ☐ Me
  - ☐ My partner
  - ☐ General practitioner
  - ☐ Surgeon
  - ☐ Nurse in the breast cancer outpatient clinic
  - ☐ Oncologist
  - ☐ Radiotherapist
  - ☐ Plastic surgeon
  - ☐ I don't want to discuss the subject
  - ☐ Other: \_\_\_\_\_
37. With which health care professional would you prefer discussing intimacy and sexuality? (*multiple answers possible*)
- ☐ General practitioner
  - ☐ Surgeon
  - ☐ Nurse on the breast cancer outpatient clinic
  - ☐ Oncologist
  - ☐ Radiotherapist
  - ☐ Plastic surgeon
  - ☐ Psychologist
  - ☐ Sexologist
  - ☐ Social worker
  - ☐ I don't want to discuss the subject with a health care professional
  - ☐ Other: \_\_\_\_\_
38. What was for you a reason **not** to start a conversation about intimacy and sexuality with a health care professional? (*multiple answers possible*)
- ☐ Inapplicable, I did ask my questions about intimacy and sexuality
  - ☐ I have no need
  - ☐ A feeling of shame
  - ☐ Intimacy and sexuality are private
  - ☐ I am too sick for discussing intimacy and sexuality
  - ☐ There is nothing to do about it
  - ☐ Intimacy and sexuality are no priority
  - ☐ I would rather discuss this subject with my partner
  - ☐ I don't have a partner
  - ☐ The health care professional is too busy
  - ☐ The health care provider didn't initiate the discussion
  - ☐ The health care professional was not open for discussing this subject
  - ☐ The health care professionals is a man
  - ☐ The age of the health care professional
  - ☐ This subject doesn't belong to a health care professional
  - ☐ Lack of privacy; I was with my partner
  - ☐ Lack of privacy; I was with friends/family
  - ☐ Lack of privacy; due to other health care professionals (for example, an intern)
  - ☐ Other: \_\_\_\_\_
39. Statement: Every breast cancer patient should be offered a conversation about intimacy and sexuality, **before treatment.**
- ☐ Agree
  - ☐ Disagree
  - ☐ I don't know
40. Statement: Every breast cancer patient should be offered a conversation about intimacy and sexuality, **during treatment.**
- ☐ Agree
  - ☐ Disagree
  - ☐ I don't know
41. Statement: Every breast cancer patient should be offered a conversation about intimacy and sexuality, **after treatment.**
- ☐ Agree
  - ☐ Disagree

- ☐ I don't know
42. At which state of treatment would you prefer to talk about intimacy and sexuality? (*multiple answers possible*)
- ☐ At the same time as the diagnosis of breast cancer
- ☐ Before chemotherapy and before surgery
- ☐ Before the operation
- ☐ After the operation
- ☐ Before the additional treatment\*
- ☐ During the additional treatment\*
- ☐ At the end of all treatments
- ☐ I don't want to discuss the subject
- ☐ Other: \_\_\_\_\_

*Results of this research*

43. Would you prefer a meeting with other patients on intimacy and sexuality after breast cancer? The results of this research will be discussed anonymously.
- ☐ Yes
- ☐ No
44. In response to this research, we are willing to invite patients for an individual conversation about intimacy and sexuality. Might we invite you for a conversation?
- ☐ Yes
- ☐ No
- ☐ If you answered "yes" to question **43 or 44**, you might fill in you contact details. It might take a while before we will contact you. You always can decide not to participate later on.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional comments:

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**Part 6: Questions about your relationship**

**If you didn't have a partner at time of the diagnosis or treatment for breastcancer, you finished the questionnaire. If you have a partner, please answer to the following questions.**

45. I have a relationship with a:
- ☐ Man
- ☐ Woman
46. Did you have a relationship **before** you were diagnosed with breast cancer?
- ☐ Yes, **go to question 48**
- ☐ No, **go to question 52**
47. Did the **diagnosis of breast cancer** have an impact on the quality of the relationship with your partner?
- ☐ Yes, the quality increased
- ☐ Yes, the quality declined
- ☐ Yes, my relationship is broken
- ☐ No, the quality didn't change
48. Did **body changes** as a result of the breast cancer treatment have an impact on the quality of the relationship with your partner?
- ☐ Yes, the quality increased
- ☐ Yes, the quality declined
- ☐ Yes, my relationship is broken
- ☐ No, the quality didn't change
- ☐ No, my body didn't change
49. Did new complaints on intimacy or sexuality have an impact on the quality of the relationship with your partner?
- ☐ No impact
- ☐ Negative impact
- ☐ Positive impact
- ☐ Inapplicable, I don't have any complaints
50. Did you discuss possible effects of the breast cancer treatment on intimacy and sexuality with your partner?
- ☐ Yes
- ☐ No, but I would have liked to discuss it
- ☐ No, no need to

51. Is it important to you that your partner is present when discussing the subject intimacy and sexuality with a health care professional?
- ☐ Yes
- ☐ No
52. Statement: The partner of every breast cancer patient should be offered a conversation about intimacy and sexuality.
- ☐ Agree
- ☐ Disagree
- ☐ I don't know
- ☐
53. How would your partner support you with possible complaints in the area of intimacy and sexuality? *(multiple answers possible)*
- ☐ By exerting as little pressure as possible on sexuality
- ☐ To talk about sexuality
- ☐ To reassure me when a sexual contact attempt fails
- ☐ By not losing intimacy
- ☐ To be involved as much as possible with my sexual complaints
- ☐ By discovering intimacy and sexuality in another way I don't know
- ☐ Inapplicable, I don't have any complaints
- ☐ Other: \_\_\_\_\_
54. How do you plan to support your partner with possible complaints in the area of intimacy and sexuality? *(multiple answers possible)*
- ☐ To talk about sexuality
- ☐ By not losing intimacy
- ☐ To involve my partner as much as possible by my sexual complaints
- ☐ By discovering intimacy and sexuality in another way
- ☐ Inapplicable, I don't have any complaints
- ☐ I don't know
- ☐ Other: \_\_\_\_\_
55. Would you have liked to receive professional help with complaints on intimacy or sexuality?
- ☐ Yes
- ☐ No
- ☐ Inapplicable, I don't have any complaints
56. Please check the box which is most applicable to you

	Totally disagree	Disagree	Neutral	Agree	Totally agree
1. My partner and I can talk well about our mutual feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I often take the time to listen to my partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. My partner and I can discuss everything	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. We try to resolve disagreements with a calm conversation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Disagreements often lead to an argument	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. My partner tends to boss me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I would like to have sex more often with my partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. My partner and I can talk easily about our sexual desires and needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I am satisfied with our sex life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I have a good relationship with my partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I am felling annoyed with my partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I am happy with my partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Thank you for participating in this research.**

You can return the questionnaire to attached envelope (no stamp required).

## Appendix B

### Questionnaire partner (translated from Dutch)

For each question, choose the most suitable answer. Thank you in advance for your effort.

#### Part 1: Demographics

57. What is your age? \_\_\_\_\_ years
58. What is your ethnicity?

- ☐ Dutch
- ☐ Other: \_\_\_\_\_
- 59. What is your gender?
  - ☐ Male
  - ☐ Female
- 60. Level of education?
  - ☐ Elementary school
  - ☐ Middle school
  - ☐ High school
  - ☐ College
  - ☐ University
  - ☐ Other: ... ..
- 61. Are you currently employed?
  - ☐ Yes
  - ☐ No, I am in between jobs
  - ☐ No, not able to work due to my illness
  - ☐ No, I am retired
  - ☐ Other: \_\_\_\_\_

### Part 2: Diagnosis and treatment

- 62. Did you already have a relationship **before** she was diagnosed with breast cancer?
  - ☐ Yes, **go to question 7**
  - ☐ No, **go to question 11**
- 63. To what extent were you concerned about your partner's health when you heard the diagnosis of breast cancer?
  - ☐ No concerns
  - ☐ Some concerns
  - ☐ Many concerns
  - ☐ Grave concerns
- 64. Have your concerns changes **after** treatment?
  - ☐ Yes, my concerns are increased
  - ☐ Yes, my concerns are declined
  - ☐ No, my concerns didn't change
  - ☐ No, I had no concerns
- 65. Did the **diagnosis of breast cancer** have an impact on the quality of the relationship with your partner?
  - ☐ Yes, the quality increased
  - ☐ Yes, the quality declined
  - ☐ Yes, my relationship is broken
  - ☐ No, the quality didn't change
- 66. Did **body changes** as a result of the breast cancer treatment have an impact on the quality of the relationship with your partner?
  - ☐ Yes, the quality increased
  - ☐ Yes, the quality declined
  - ☐ Yes, my relationship is broken
  - ☐ No, the quality didn't change
  - ☐ No, my partner's body didn't change
- 67. If your partner is breast cancer-free, are you afraid that the breast cancer may come back?
  - ☐ Inapplicable
  - ☐ Not afraid
  - ☐ A bit afraid
  - ☐ Afraid
  - ☐ Very afraid

### Part 3: Your experience about intimacy and sexuality after disease

- 68. Did you discuss possible effects of the breast cancer treatment on intimacy and sexuality with your partner?
  - ☐ Yes
  - ☐ No, but I would have liked to discuss it
  - ☐ No, no need to
- 69. Did you experience complaints in intimacy or sexuality before the diagnosis of breast cancer?
  - ☐ Yes, **go to question 14**
  - ☐ No, **go to question 17**
- 70. Did new complaints on intimacy or sexuality have an impact on the quality of the relationship with your partner?

- ☐ No impact
  - ☐ Negative impact
  - ☐ Positive impact
  - ☐ Inapplicable, I don't have any complaints
71. On a scale of 0 to 10, in which amount did you suffer from these complaints?  
0 means no suffering, 10 means a lot of suffering  
Grade: ... ..
72. To what extent did you find it difficult to handle changes in intimacy and sexuality within your relationship?
- ☐ No difficulties
  - ☐ A little difficult
  - ☐ Difficult
  - ☐ Very difficult

**Part 4: Information about intimacy and sexuality**

73. Did you need information about possible intimacy or sexuality complaints due to breast cancer and treatment?
- ☐ Yes
  - ☐ No
74. Did you at some point receive any information about intimacy and sexuality and possible complaints due to treatment of your partner?
- ☐ Yes, **go to question 19**
  - ☐ No, **go to question 23**
75. At what stage did you receive the information about intimacy and sexuality? (*multiple answers possible*)
- ☐ At the same time as the diagnosis of breast cancer
  - ☐ Before chemotherapy and before surgery
  - ☐ Before the operation
  - ☐ After the operation
  - ☐ Before the additional treatment\*
  - ☐ During the additional treatment\*
  - ☐ At the end of all treatments
  - ☐ Other: \_\_\_\_\_

\*Additional treatment: chemotherapy, radiotherapy, and/or endocrine therapy

76. Did you have to ask for information about intimacy or sexuality?
- ☐ Yes, I had to ask for this information by myself
  - ☐ No, the care provider gave the information to me
  - ☐ No, it was clear to me where I could find information (for example, a flyer or on the web)
77. Who gave you the information about intimacy and sexuality? (*multiple answers possible*)
- ☐ General practitioner
  - ☐ Surgeon
  - ☐ Nurse in the breast cancer outpatient clinic
  - ☐ Oncologist
  - ☐ Radiotherapist
  - ☐ Plastic surgeon
  - ☐ Psychologist
  - ☐ Sexologist
  - ☐ Social worker
  - ☐ Someone else: \_\_\_\_\_
78. How did you receive information about intimacy and sexuality? (*multiple answers possible*)
- ☐ Patient flyer
  - ☐ Via other (breast) cancer patients
  - ☐ By an information moment for patients with breast cancer
  - ☐ By Dutch Breast Cancer Society (Borstkankervereniging Nederland)
  - ☐ By Dutch Cancer Society (KWF Kankerbestrijding)
  - ☐ By a webpage about breast cancer and sexuality
  - ☐ In a conversation with a health care professional
  - ☐ Other: \_\_\_\_\_
79. Did you actively search for information about intimacy and sexuality? (*multiple answers possible*)
- ☐ No, I didn't search for information
  - ☐ Yes, on the Internet
  - ☐ Yes, via Dutch Breast Cancer Society (Borstkankervereniging Nederland)
  - ☐ Yes, via Dutch Cancer Society (KWF Kankerbestrijding)
  - ☐ Yes, via other (breast) cancer patients

- ☐ Yes, via family or friends
- ☐ Other: \_\_\_\_\_
- 80. Are you satisfied with the information about intimacy and sexuality?
  - ☐ Yes, go to question 26
  - ☐ No, **go to question 25**
  - ☐ Inapplicable, **go to question 26**
- 81. What could have been better about the information? (*multiple answers possible*)
  - ☐ The amount was insufficient
  - ☐ The information was too general; it was not about my situation
  - ☐ The content of the information was incorrect
  - ☐ The moment of the information was too late
  - ☐ The moment of the information was too early
  - ☐ I have asked for information, but I didn't receive any
  - ☐ The health care professional should have given me the information
  - ☐ I have no need for information
  - ☐ Other: \_\_\_\_\_
- 82. What is, according to you, the best way of receiving information about intimacy and sexuality? (*multiple answers possible*)
  - ☐ Patient flyer
  - ☐ Via an application on a tablet or phone (e-health)
  - ☐ By a webpage about breast cancer and sexuality
  - ☐ By Dutch Breast Cancer Society (Borstkankervereniging Nederland)
  - ☐ By Dutch Cancer Society (KWF Kankerbestrijding)
  - ☐ By a patient forum on the Internet
  - ☐ By a group meeting with other patients led by a health care professional
  - ☐ In a conversation with other (breast) cancer patients
  - ☐ In a conversation with a health care professional
  - ☐ None, I have no need for information
  - ☐ Other: \_\_\_\_\_
- 83. At which moment, during treatment, would you prefer to receive information about intimacy and sexuality? (*multiple answers possible*)
  - ☐ At the same time as the diagnosis of breast cancer
  - ☐ Before chemotherapy and before surgery
  - ☐ Before the operation
  - ☐ After the operation
  - ☐ Before the additional treatment\*
  - ☐ During the additional treatment\*
  - ☐ At the end of all treatments
  - ☐ Other: \_\_\_\_\_

\*Additional treatment: chemotherapy, radiotherapy, and/or endocrine therapy

#### Part 5: Discussing intimacy and sexuality with a health care professional

- 84. Is it important to you that you are present when the subject intimacy and sexuality is discussed by a health care professional?
  - ☐ Yes
  - ☐ No
- 85. Statement: **The partner** of every breast cancer patient should be offered a conversation about intimacy and sexuality.
  - ☐ Agree
  - ☐ Disagree
  - ☐ I don't know
- 86. With which health care professional would you prefer discussing intimacy and sexuality? (*multiple answers possible*)
  - ☐ General practitioner
  - ☐ Surgeon
  - ☐ Nurse in the breast cancer outpatient clinic
  - ☐ Oncologist
  - ☐ Radiotherapist
  - ☐ Plastic surgeon
  - ☐ Psychologist
  - ☐ Sexologist



- ☐ Social worker
- ☐ I don't want to discuss the subject with a health care professional
- ☐ Other: \_\_\_\_\_

87. At which state of treatment would you prefer to talk about intimacy and sexuality? (*multiple answers possible*)

- ☐ At the same time as the diagnosis of breast cancer
- ☐ Before chemotherapy and before surgery
- ☐ Before the operation
- ☐ After the operation
- ☐ Before the additional treatment\*
- ☐ During the additional treatment\*
- ☐ At the end of all treatments
- ☐ I don't want to discuss the subject
- ☐ Other: \_\_\_\_\_

\*Additional treatment: chemotherapy, radiotherapy, and/or endocrine therapy

88. Would you have liked to receive professional help with complaints on intimacy or sexuality?

- ☐ Yes
- ☐ No
- ☐ Inapplicable, I don't have any complaints

#### Part 6: Questions about your relationship

89. How would your partner support you with possible complaints in the area of intimacy and sexuality? (*multiple answers possible*)

- ☐ By exerting as little pressure as possible on sexuality
- ☐ To talk about sexuality
- ☐ To reassure me when a sexual contact attempt fails
- ☐ By not losing intimacy
- ☐ To be involved as much as possible with my sexual complaints
- ☐ By discovering intimacy and sexuality in another way I don't know
- ☐ Inapplicable, I don't have any complaints
- ☐ Other: \_\_\_\_\_

90. How do you plan to support your partner with possible complaints in the area of intimacy and sexuality? (*multiple answers possible*)

- ☐ To talk about sexuality
- ☐ By not losing intimacy
- ☐ To involve my partner as much as possible by my sexual complaints
- ☐ By discovering intimacy and sexuality in another way
- ☐ Inapplicable, I don't have any complaints
- ☐ I don't know
- ☐ Other: \_\_\_\_\_

91. Please check the box which is most applicable to you

	Totally disagree	Disagree	Neutral	Agree	Totally agree
1. My partner and I can talk well about our mutual feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I often take the time to listen to my partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. My partner and I can discuss everything	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. We try to resolve disagreements with a calm conversation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Disagreements often lead to an argument	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. My partner tends to boss me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I would like to have sex more often with my partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. My partner and I can talk easily about our sexual desires and needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I am satisfied with our sex life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I have a good relationship with my partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I am feeling annoyed with my partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I am happy with my partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

92. Would you prefer a meeting with other patients on intimacy and sexuality after breast cancer? The results of this research will be discussed anonymously.

- ☐ Yes
- ☐ No

93. In response to this research, we are willing to invite patients for an individual conversation about intimacy and sexuality. Might we invite you for a conversation?

- ☐ Yes
- ☐ No

If you answered “yes” to question **36 or 37**, you might fill in you contact details. It might take a while before we will contact you. You always can decide not to participate later on.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Email address: \_\_\_\_\_

Additional comments:

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**Thank you for participating in this research.**

You can return the questionnaire to attached envelope (no stamp required).